Arkansas

Spinal Courier No. 1 A Publication of the Arkansas State Spinal Cord Commission October, 1990

ASSCC Receives PVA Grant

The Arkansas State Spinal Cord Commission was recently awarded a grant from the Paralyzed Veterans of America Spinal Cord Injury Education and Training Foundation. The project, entitled "Developing A Spinal Cord Injury Education and Resource Center" was one of nine funded by PVA this year.

"We are pleased and excited to be working in cooperation with PVA on this project" said Cheryl Vines, Executive Director. "This will allow us to make resources on spinal cord injury available to the people who need them."

According to a recent needs assessment of spinal cord disabled individuals in Arkansas, clients and their families often do not know where to turn for help in coping with the everyday problems associated with their disability. In addition, health care professionals working with the spinal cord injured in Arkansas cite a need for a free resource and information center, where they can

learn to assist their clients more effectively and accurately.

The Arkansas State Spinal Cord Commission will fill this need by establishing an education resource center where people with spinal cord injuries as well as their health care professionals can turn for resource development, information and referral.

The center will acquire books, journals, videotapes, periodicals, catalogs, and other resource materials during the first year of the project. In year two, smaller regional centers will be set up in Case Manager offices throughout the state. The center will disseminate resources and information to people with disabilities and health care professionals through a quarterly newsletter and a series of fact sheets on various aspects of SCI.

More information on the project will be available in the Spinal Courier as the Center develops.

Evans Appointed To Commission

Governor Bill Clinton recently appointed Grover Evans of Jonesboro to membership on the Spinal Cord Commission. Evans replaces James Gary who resigned earlier in the year and will assume a term ending in 1999.

Evans is a quadriplegic secondary to a motor vehicle crash in 1977. He is well known for his many civic involvements, including serving as a Jonesboro City Alderman. He also serves as a member of the recently formed Early Childhood Commission. A local businessman and accomplished wheelchair athlete, Mr. Evans speaks frequently at schools and other events on disability awareness and the rights of people with disabilities.

"The only limitations that exist are the ones we make for ourselves regarding our physical conditions," says Evans, "we are all accountable and functional members of our society."

ASSCC GETS NEW PHONE NUMBERS



The Arkansas State Spinal Cord Commission Little Rock offices phone numbers have been changed to the following:

	<u>Old #</u>	New#	
Central Office	371-1283	324-9624	
Executive Director	371-2929	324-9626	
Prevention Program	371-3409	324-9627	
Research/Grants Office	371-3011	324-9620	
Case Management Program	371-1804	324-9628	

Arkansas Spinal Courier

Published quarterly by Arkansas State Spinal Cord Commission

Cheryl L. Vines Executive Director

Thomas L. Farley Editor

Published in cooperation with the Paralyzed Veteran's Association of America, Spinal Cord Injury Education and Training Foundation.

BUCKLE UP!

Spinal Courier Enlarged, Sets Publication Schedule

The Arkansas Spinal Courier has expanded its number of pages, per issue, from 4 to 6 and will be published quarterly instead of bimonthly. The expansion of the newsletter was made possible with grant funds recently received from the Paralyzed Veteran's Administration. (See PVA Grant article, page 1).

Tom Farley, Newsletter Editor, said that the larger size would allow a wider variety of spinal cord disability issues to be included and for a greater amount of educational information to be discussed.

1991 Newsletter Schedule

Deadlines for the submission of articles and photos for the 1991 issues of the Spinal Courier are as follows:

<u>Issue</u>	<u>Deadline</u>		
January, 1991	12-22-90		
April, 1991	3-29-91		
July, 1991	6-29-91		

Arkansans Compete Internationally

Five Arkansans were selected to compete in international wheelchair sports competitions this summer. Four Rollin' Razorbacks, Darren Schenebeck and Tim Kazee of Little Rock, and Gary Woodring and James Coughlin of North Little Rock were selected for basketball competitions. Grover Evans of Jonesboro was selected for table tennis.

Schenebeck and Kazee competed on the U.S. team in the Gold Cup World Wheelchair Basketball Championships in Brugge, Belgium in August. Rollin' Razorback Coach Harry Vines was the team head coach and Dr. Terry Winkler of UAMS was team physician. Winning six games against the premiere teams in the world, the U.S. team came up one point short in the championship game, losing to France 62-61 and garnering the silver medal.

Woodring and Coughlin competed in July in wheelchair basketball competition at the International Stoke Mandeville Games in Aylesbury, England. Their team proved a formidable one, winning every game they played and defeating Israel in the championship 73 to 28 to win the gold!

Evans, a Spinal Cord Commission member was selected to the U.S. team that traveled to Caracas, Venezuela for the Pan-American games. Grover is a quadriplegic and was slated to compete in class 1-A table tennis competition. Unfortunately, due to a last minute illness, he was unable to make the trip.

Schenebeck, a computer programmer for the State and Kazee, a teller at Worthen Bank, both sustained Spina Bifida. Woodring, a traumatic paraplegic is assistant manager of United Medical in Little Rock. All three are clients of the Spinal Cord Commission. Coughlin, a below-knee amputee is a student at UALR. Each represented Arkansas and the U.S. this summer and we offer our congratulations on their accomplishments.

Equipment Warranty Often Overlooked

Equipment purchased by ASSCC for use by clients is often covered by a manufacturer's warranty. Defective equipment, under warranty, can often be replaced for free or minimal cost if it is returned to the dealer where it was purchased during the warranty period. Some items have lifetime warranties, so always check with your Case Manager.

If you experience the failure or breakage of a piece of equipment, DO NOT THROW IT AWAY! Instead, notify your Case Manager immediately to pick up the defective piece of equipment. The Case Manager will return the defective part to the dealer/company for credit and make arrangements to get you a replacement part.

MEDICAL ALERT

Because of the potential seriousness of Autonomic Dysreflexia and the lack of knowledge among medical personnel about this complication, the Spinal Cord Com-

mission has developed
a "Medical
Alert" card.
This is a plastic
laminated card the
size of a credit card
and should be carried
at all times in the wal-

let of anyone who might be subject to Autonomic Dysreflexia (spinal cord injury above the level of T6). The card contains information about how to recognize and treat Dysreflexia.

To request a card, please contact your Case Manager.

My First Fishing Experience

By Sonia (Sunshine) Anthony

Editor's foreword:

On August 6th the Arkansas Spinal Cord Commission, the Arkansas Game and Fish Commission and the Spa Area Independent Living Services jointly sponsored a fishing derby for people with disabilities on Lake Hamilton. Over 300 people attended this recreational activity. It was a monumental day for people with spinal cord injuries. Some people were given an opportunity to fish for the first time in their life. Others were able to fish for the first time since their injury.

Bettie Tapp, ASSCC Case Manager for the area, worked hard to coordinate this fishing derby to provide folks with spinal cord disabilities the same opportunitites to vacation as the general public. The following letter relates one person's experience that day.



When I first arrived at the August 6th Fishing Tournament, I wasn't terribly excited at the prospect of touching those slimy little worms and unhooking the catfish from the

line, so I went to the new pier to see if it was as nice as the one near my home. It's a lot bigger but just as nice. After sitting there for a while, I could see that everyone was having fun by the edge of the water, fishing. When I got there my friend Don asked me if I would like to use one of his fishing poles and I said, "Why not?" But I also told Don that I would not touch those worms.

I sat there for an hour and a half and nothing. That was so very discouraging. My husband Johnfox was at the Pier looking around and I took a little break from my not so-good-fishing, to go sit by him and tell him that I was having the worse luck in the world. After talking to him I regained my confidence and I decided to try it once more.

Almost as soon as my hook hit the water I caught my very first fish! I looked at my husband Johnfox with excited eyes and he helped me reel it in. I never thought I could get so excited about catching fish, but I did!

As soon as Don got the catfish off the hook and baited it again, I tried it again. In no time at all, I had a second fish on my line. It was great, but all my muscles were so sore from fighting to bring it in. After the second one I



Sonia Anthony with her catfish catch of the day.

caught two more and reeled them in myself.

After reeling in three large catfish, I was pooped out and so I quit for the evening. I gave my catch to a little boy named Dennis, who didn't catch a fish but actually caught a few humans, but threw them back in. Dennis was happy that he finally caught some catfish even if he only caught them from me.

I would like to thank all the sponsors and everyone who helped make the tournament a big success. And I would also like to especially thank Don who loaned me his pole and baited my line. THANK YOU!

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Arkansas State Spinal Cord Commission
1120 Marshall Street, Suite 207
Little Rock, AR 72202

Please Place Stamp Here

Arkansas State Spinal Cord Commission 1120 Marshall Street, Suite 207 Little Rock, AR 72202

Readership Survey

Dear Reader: Please give us your opinion. We'd ling and informative. With your input and return this survey by November YOUR NAME! Cut this page out of dress is on the outside. Put a stamp	it we can ma 30, 1990. T f the newslet	ke it more whis is an and ter and fold	valuable to you onymous surve l where indicat	 Please con ey! DO NOT ed so the retu 	nplete SIGN	
1. How many stories do you	ı read in e	ach issue	of the Spin	nal Courie	r?	
almost all more than half less than half none						
2. Rate the Spinal Courier on each of the following:						
	Excellent	Good	Fair	Poor		
Your overall opinion						
Article Variety						
Ease of reading						
Appearance						
3. Articles are generally:	too lo	ong	too short	just righ	t	
4. Please rate the following article subjects:						
 Medical	Very Interesting	Some Interest	Slightly Interesting	No Interest		
ASSCC Activities						
Client Successes & Activities						
Short Information Stories						
5. I'd like to see an article of	on:				., <u>.</u>	
6. Comments:						
						

Medical Insurance

by Shirley McCluer, M.D.

Many of you have already learned the hard way that medical insurance for someone with spinal cord injury is extremely difficult to obtain and frequently does not meet all of your needs. The cost of health care in general is increasing so rapidly that it is a major concern for everyone and there is no easy answer. The options that are currently available are:

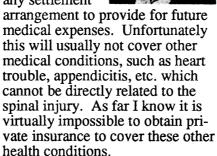
Medicare: Any worker who qualifies for Social Security Disability Income (SSDI) will be eligible for Medicare starting two years after the first Social Security Disability payment. Although there are many limitations, this is probably the best coverage you could have except it does not pay for medications. However you must continue to be unemployed.

Medicaid: Individuals who have no income and qualify will be eligible for Medicaid. This program varies from state to state. Unfortunately in Arkansas the lack of state funds has resulted in recent dramatic cutbacks for Medicaid services which will affect most spinal injured individuals. There are restrictions on the number of physician visits, hospital days and medical prescriptions which will be covered. Medicaid covers very little durable medical equipment.

Medicare/Medicaid: Some individuals are eligible for both Medicare and Medicaid which can be very helpful because each one pays for some services that are not covered by the other. In addition, Medicaid will often assume the balance of medical bills that Medicare does not pay.

Worker's Compensation: Anyone whose spinal injury was due to an on-the-job injury will usually be covered by Worker's Compensation for any medical expenses

resulting from the injury. It is important for any settlement



Group Insurance: Any spinal injured individual who is employed by a company with group insurance or who is an eligible family member (spouse or dependent) of an employee will be eligible for the benefits of the company's insurance program. There is often a one year or more waiting period for coverage of preexisting conditions. Some companies may permanently exclude spinal injury because they know it can be very expensive.

Many companies have placed severe restrictions on the type of benefits they will provide for their employees. These include such things as limiting the physician or hospital you may use, and placing strict limits on what is "medically necessary." Frequently rehabilitation is not covered and medical equipment such as wheelchairs, tub benches, bedside commodes. etc. are not considered necessary. If you are covered by Group Insurance you should review the benefits and limitations very carefully! Talk to your insurance carrier to discuss your medical needs. You may also appeal decisions that the insurance company makes related to providing services. Many insurance companies require precertification or preauthorization before they will provide full coverage. If you do not contact them in advance, you may be liable for some of the costs.

Unfortunately many individuals are not eligible for any of the above. A prime example is the individual who has never worked and does not qualify for Social Security Disability, or the selfemployed individual who cannot. obtain private insurance. If any of you have been fortunate enough to find solutions to some of these problems, please let your Case Manager know so the information can be passed along to others. If you have had special problems with getting the type of benefits that you think you deserve, you can write to your congressman, (with a copy to your Case Manager). Our federal government is currently struggling to find some way to assure access to good health care for all citizens and it is helpful for them to know the kind of problems that exist.

Spinal Cord Injury Grant Renewed for Third Year

The Arkansas State Spinal Cord Commission's grant entitled, Spinal Cord Injury Prevention and Surveillance, has been renewed by the Centers for Disease Control. The third and final grant year began on October 1, 1990 and will terminate on September 30, 1991.

The project which spent most of the first two years collecting data and setting up a surveillance system for Arkansas, will concentrate on prevention activities and information dissemination for the third year.

Two additional staff will be hired to work on the grant for the third year. First, a Health Educator will establish a spinal cord injury prevention program in the areas of diving and farm related injuries. Second, a Research Analyst will be hired to write several papers about how and under what circumstances SCI occurrs. Several papers suitable for publication are planned.

Ten Tips on Disciplining Children from a Wheelchair

"An ounce of prevention is worth a pound of cure" goes the old saying, and Jean Moore agrees. This theory, plus lots of love, is the basis of rearing children from a wheelchair, she feels after 28 years of motherhood. She outlines ten helpful tips to prevent frustration and enjoy parenthood.

- 1. Spend time with your children even when you feel you should be doing something else. You can get more work done with fewer interruptions if the children feel they have their fair share of your attention. Order your priorities and pare your work to the essentials. You can't afford the energy of worrying over what is not done.
- 2. Prevent children from getting too tired or hungry. Try to make meals a relaxing time and bedtime peaceful and quiet.
- 3. Water is wonderful therapy. Let children splash in the bathtub or play in a pail or sink full of water. Even in winter, standing at the sink on a stepstool, a child in a plastic apron can have fun sailing boats, washing dishes, or just pouring water.
- 4. All kinds of hand work make a child feel good about himself. We kept a "school box" for preschoolers--a carton containing crayons, pencils, scissors, paints, play-doh, clay, and paper. While older brother and sister were at school and I did kitchen work, the athome child played at the kitchen table. This minimized and localized the mess and was a sociable time for the two of us. The school box helped to structure the day and make him feel included in "school." Add to the contents as your child's interest change.
- 5. Read aloud to your children. We started showing pictures to our children when they were six months old and read to them until

they were 12! This stimulates their imaginations. Children can enjoy hearing books which they may not be ready to read themselves. A quiet time of reading in the evening makes bedtime pleasant and relaxing with little fuss about going to sleep. An after lunch quiet hour of reading prevents a buildup of fatigue and irritability as a result of prolonged physical activity.

- 6. Rules and routine make a child feel secure. He knows what to expect when there is organization and supervision of his day. Of course, you plan surprises, too!
- 7. Give choices whenever possible and explain them carefully. For example, your child wants to go out doors in tennis shoes on a rainy day. You want him to wear boots. Give him the choice of going outside with boots or staying inside without them. It works!
- 8. try not to use too many words. Explain as clearly and as simply as possible. If words are ineffective, take appropriate action by moving the child, sending him up to his room, or whatever will resolve the situation.
- 9. As children grow older, keep the lines of communication open. If communication gets too "hot," sometimes a cooling off period will lead to a calm solution. Don't be afraid to admit you are wrong and don't be afraid to change your mind. Honesty will help keep communication open and before long you'll all be adults meeting on an equal basis.
- 10. Don't fall into the trap of thinking that the problems you have with your children are due to your being in a wheelchair! Your children are no different from those of your more athletic neighbors. When measured against other children you know, you will

find that your own are more capable than most. Their help and cooperation have been needed and they have the advantage of having learned to do many things earlier than most others. They are not disadvantaged because of your physical limitations. In fact, they are probably more independent than most children their age.

Source: Reprinted with permission, © 1989. An Accent Guide, "Parenting," an ACCENT Special Publication.

ICAN Volunteers Needed!

by Karen Bays

ICAN, the Increasing Capabilities Access Network, is seeking individuals to serve as regional technology specialists in the following counties: Randolph, Clay, Lawrence, Greene, Craighead, Mississippi, Poinsett, Grant, Jefferson, Arkansas, Cleveland, Lincoln, Desha, Bradley, Drew, Chicot, and Ashley.

Duties include: providing information about ICAN, its services, and the benefits of assistive technology ("tools for living"); help establish local networks that will identify and develop solutions for barriers in the community; help identify local training needs and coordinate training in the community.

Qualifications for applicants include: willingness and availability to work with others in the community; knowledge of the benefits of assistive technology and existing services in the community for individuals with disabilities and/or older adults; knowledge of disability and/or older adult related issues.

Individuals with disabilities and their family members are encouraged to apply. For more information contact Karen Bays at ICAN (Voice/TDD) 1-800-828-2799.

ROLLIN' RAZORBACKS

1990-91 SEASON

November 3-4, 1990 (Home)

"Central Arkansas Rehabilitation Hospital Invitational"
Lakeshore, AL - E.P.V.A., N.J. - Tulsa, OK
Referee Workshop, Saturday
Games start at 9:00 a.m., Saturday and Sunday

November 4, 1990 (Home)

University of Arkansas Red-White Game, Barton Coliseum, Half-time Exhibition - 7:00 p.m.

December 1-2 (Away) "Kansas City Invitational"

December 7-8-9 (Away) "American Airlines Classic," Dallas, TX

December 15-16 (Home)

"United Medical/Quickie Invitational" Kentucky - Chicago - Ottawa, Canada Medical Classification Workshop, Saturday Games start at 9:00 a.m., Saturday and Sunday

January 5-6 (Home) "Worthen Classic"

Music City, TN - Golden State 76'ers, CA - Kitchner, Canada Games start at 9:00 a.m. Saturday and Sunday

January 12-13 (Home)

"Reebok/Hampton Inn Invitational"
Salt Lake City Utah - Minnesota - Ft. Smith, AR
Games start at 9:00 a.m., Saturday and Sunday

January 19-20 (Away)

"Music City Invitational," Nashville, TN

February 2-3-4 (Away)

"Bluegrass Invitational," Lexington, KY

February 9-10 (Home)

"U.S. Pizza/Coors Light Invitational"

Dallas Mavericks, TX - Kansas City Pioneers, KS -St. Louis, MO

Games start at 9:00 a.m., Saturday and Sunday

February 16-17 (Away) "Pioneer Classic" - Birmingham, AL

Regional Playoffs, February 23-24, 1991

Sectional Playoffs, March 9-10, 1991

March 22-23, 1991

"N.W.B.A. Men's Final Four" - Little Rock, AR Contact Cheryl Vines at (501) 324-9624)

Home Games Played at Sylvan Hills High School (Hwy. 107 North of Sherwood)

Sixty One Campers Attend Aldersgate

The Arkansas State Spinal Cord Commission sponsored two weeklong sessions this year at Camp Aldersgate. The camps were held in cooperation with MedCamps of Arkansas, Aldersgate Methodist Camp and theSpina Bifida Association of Arkansas.

Thirty one campers, aged 12 through 16, attended from June 10 - 15 and 30 campers, aged 6 through 11, attended from July 1 - 6.

In addition to the normal camp activities of swimming, cookouts and boating, the Arkansas Rollin' Razorbacks basketball team conducted a wheelchair basketball clinic. As the photos below indicate, it was a big success!



Riannon Johnson tries her hand at the free throw line.



Wesley Coddington and Razorback Tim Kazee participate in the baskeball clinic.

The Arkansas Chapter of the National Ataxia Foundation

Cordially invites you to the 1991 convention February 8, 9 & 10th, 1991 Excelsior Hotel in Little Rock "Genetics, Genealogy and Our Future." Call Judy Cox at 767-4876 for more information

SECONDARY DISABILITIES GRANT EXTENDED

The Arkansas State Spinal Cord Commission's Secondary Disabilities grant has been extended for nine months until June 30, 1991. The purpose of the grant, which is funded by the National Centers for Disease Control in Atlanta, is to document the incidence and cost of pressure sores and to provide in-home education for persons newly injured and for persons with chronic pressure sores.

The extension will allow the analysis and dissemination of the results of the project which began in October, 1989. Part of the results will include an overall strategic plan for the development of protocols for the prevention of pressure sores in a variety of patient settings. The project has progressed well this past year and has been able to meet most of its established goals and objectives.

Do You Have a Smoke Detector?

Smoke detectors save lives by giving individuals with handicaps precious time to escape in the event of a fire. Every home should have one and are an absolute must for persons living alone.

The Little Rock Fire Department will supply and install smoke detectors (free of charge) to individuals with handicaps living in single resident homes (no apartments). This offer is only for Little Rock city residents who do not have smoke detectors and the while supply of detectors lasts.

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WANTED!

Families with Ataxia by Judy B. Cox

Recently, I received a letter from a lady living in Fort Smith, who had never met anyone else who had the genetic disorder. I completely understand her emotional frustrations, as I was 25-years-old before I "accidentally" met a dorm-mate at college with Friedreich's Ataxia. In 1985, I attended my first national NAF convention.

The second I rolled into the meeting room, I was instantly accepted as a human being by 300 other NAFers! We shared good and bad experiences as well as tips on ways of coping-physically and emotionally with people who knew exactly what we were going through! By the end of the convention, we learned from Dr. B. Keats that we were all genetically related as well! Now, the meetings have taken on a flavor of family reunions packed with up-todate medical and practical info we need now!

Show your Arkansas spirit and join us at the National Ataxia Foundation 1991 Convention in Little Rock in February. You won't regret it.

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